

POLIO NETWORK NEWS

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Sixth International Post-Polio and Independent Living Conference

NEW SWALLOWING PROBLEMS IN AGING POLIO SURVIVORS

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In the normal swallowing process, three phases are typically described. The oral phase involves food being placed in the mouth, chewed if necessary, and positioned or formed into a ball (bolus) which is then moved backwards to the anterior faucial arch, an area near where the tonsils are, or used to be, and where the swallow response is triggered. During the pharyngeal phase, three things happen simultaneously. The tongue pumps the bolus back into the pharynx, the epiglottis, (a chunk of cartilage near the base of the tongue), slams down on top of the airway, the larynx (voice box) elevates slightly, and the vocal chords close. These activities prevent aspiration (food or liquid from entering the airways). If the synchrony of any of these is disturbed in any way, significant problems can occur. At the same time, the third and final phase of swallowing is occurring, a coordinated muscular activity which transports the bolus through the throat where a small sphincter (muscle) at the top of the esophagus called the cricopharyngeus relaxes (dilates) so that the bolus can enter the esophagus and eventually the stomach.

In 1988, three individuals triggered my interest in swallowing problems of post-polio individuals. They had a mean age of about 53 and were between 30 and 60 years post-onset. All complained of coughing and the sensation of food sticking in their throats. Examination found that some had reduced strength in oral musculature, some had problems with pharyngeal transit, and others had a delayed swallow response. Although there was no aspiration, all three were judged to be at risk. In 1991, a project I was involved with sent out a questionnaire to post-polio individuals. Twenty-nine of the 109 respondents reported periodic or consistent problems with their swallowing. Of 21 studied, 20 had some type of swallowing dysfunction, some with multiple problems. Nine had problems with bolus control or weakness of the musculature, four had a delayed swallow response, and 17 had problems with pharyngeal transit. While none aspirated, two were judged to be at significant risk.

PROBLEMS WITH SWALLOWING REPORTED IN THE LITERATURE ...

In 1991, a study published in *The New England Journal of Medicine* was conducted by Barbara C. Sonies, PhD, and Marinos C. Dalakas, MD. They followed 32 individuals. Only 14 of the 32 reported swallowing problems, but when examined 31 had objective signs of difficulty with swallowing. Problems were found during the pharyngeal phase, with pooling in the valleculae, the V-shaped space formed by the base of the tongue and the epiglottis. Two individuals with pooling aspirated.

Another paper published in 1991 by Alice Silbergleit, MA, et al, studied 20 post-polio individuals with a mean age of 49, 17 to 66 years post-onset of acute polio. Of these, 75% percent were noted to have reduced pharyngeal transit and pooling. Some also reported problems with esophageal motility and weakness of the oral musculature. Two individuals aspirated.

INTERACTION BETWEEN BREATHING AND SWALLOWING ...

Breathing and swallowing are reciprocal functions. When swallowing occurs, breathing halts. Seventeen of the 20 individuals in our study who had swallowing problems also had significant problems with decreased breathing capacity. There were some individuals with minimal swallowing problems, while others with very significant problems. Both groups also had moderate or severely reduced breathing capacities. It can be concluded that, although breathing problems can complicate or hinder swallowing, one cannot be predicted from the other. Significant breathing problems will not necessarily predict swallowing problems.

Currently, we are studying seven of the 15 of the original group of 21. We did a breathing assessment, a swallowing evaluation, and a vocal assessment because we are now looking at problems with voice. We measured strength and function of the oral musculature, ran a modified barium swallow, conducted pulmonary function testing, and voice testing.

Of six individuals who demonstrated swallowing problems during the initial assessment, three demonstrated an increase in the severity of their swallowing problems, and three remained essentially unchanged. Generally speaking, those individuals who were most severely involved from the initial assessment were the individuals who demonstrated the most significant progression. Again, there was no aspiration, but the two who had been at risk previously, were judged to have increased risk. All five of the individuals who had significant breathing problems earlier had their breathing capacity diminished over the four year period.

DIAGNOSIS ...

The modified barium swallow procedure is absolutely critical, not only for diagnosis, but also for focusing on the management of swallowing problems. It defines the physiology of the swallow. In addition to the standard modified barium swallow (MBS) procedure, we added what we call stress testing. Just because an individual goes through the standard MBS procedure and does not have difficulty does not mean that over the course of a normal meal they will not experience difficulties. In the stress testing, we increase the quantity of liquids, purées or solids for swallowing, and attempt to tax the swallowing system. We have also tested people after a full meal when there might be some fatigue, or we bring them in after a normal workday when there might be a fatigue factor as well.

MANAGEMENT ...

Compensatory positioning or relatively minor adjustments in posture during swallowing can significantly affect the swallow. Basic changes, such as dropping the chin or turning the head can help, the rationale being that many times the weakness in the pharynx is unilateral (on one side) and that by turning the head, the weakened side of the pharynx is shut off, forcing the bolus to go down the more intact, stronger side. Other management suggestions include dietary modifications and avoiding meals when fatigued. Longitudinal monitoring of swallowing problems, including pulmonary function testing is recommended. □

ADDITIONAL INSIGHTS

LARYNGEAL FUNCTION IN POST-POLIO PATIENTS by Brian P. Driscoll, MD and Carol Gracco, PhD (Yale School of Medicine), Carl Coelho, PhD, et al, was presented at the Eastern Section meeting of the Triological Society, Ottawa, Ontario, Canada, January 1994.

Their conclusions include ... "each of the nine subjects in this group demonstrated some form of voice deficit. In the case of reduced or weakened glottic closure, voice treatments alone, or in combination with surgical intervention such as thyroplasty to improve closure seems highly appropriate. In many cases, neither the diagnostic examination or rehabilitation had been suggested during the 20-year course post-polio even in the face of overt symptomology."

DR. COELHO referred to studies conducted by Barbara C. Sonies, PhD, Chief of Speech Language Pathology, and Marinos C. Dalakas, MD, Neurologist, at National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health. Dr. Sonies contributed Chapter 8, *LONG-TERM EFFECTS OF POST-POLIO ON ORAL-MOTOR AND SWALLOWING FUNCTION IN POST-POLIO SYNDROME*, edited by Lauro S. Halstead, MD, and Gunnar Grimby, PhD.

The additional insights below are extracted from Dr. Sonies' chapter.

It appears that some individuals have speaking or swallowing problems of which they are unaware and which slowly emerge in the same manner as has been seen with limb muscles. This progression of symptoms in limb muscles may cause new disabilities. However, swallowing problems, and associated complications such as aspiration pneumonia, can be life-threatening.

Many, but not all, individuals with swallowing problems report having had acute bulbar polio. It appears that the more severe the original condition the greater the likelihood of new problems. In their study of 32 individuals, 31 had some difficulty with swallowing, even though only 14 reported being aware of symptoms. It should be noted that the severity of the swallowing problems found in the individuals reporting problems were significantly greater than those who did not. Normal aging does not cause changes in speech and swallowing, so any new signs of problems most likely are due to neuromuscular changes.

Common complaints reported by post-polio individuals included: intermittent choking on food, pills sticking in the throat, difficulty swallowing pills, food sticking in the throat, coughing during meals, and difficulty swallowing.

Individuals with suspected swallowing problems should seek an evaluation from a speech pathologist with expertise in dysphagia (swallowing). This evaluation will include a thorough history of eating, a clinical examination of swallowing, and a videofluorographic examination of the oral and pharyngeal swallow. Persons with complaints of indigestion may need evaluation of the esophagus — which can be done during the modified barium swallow study.

None of the individuals in the follow-up study at NINDS aspirated. Credit for improvement is given to the cooperation between therapists who developed the treatment plans and polio survivors who carried out suggested strategies.



MARYLOU BREWER, RN, *Director, Training and Information Dissemination, NIDRR Research and Training Center, Rehabilitation in Neuromuscular Diseases, Department of Physical Medicine and Rehabilitation, University of California, Davis, California 95616-8655 describes their current swallowing research project directed by E.R. Johnson, MD.*

The goals are:

1. To evaluate swallowing disorders in neuromuscular disease;
2. To develop and validate quantitative measurements of pharyngeal transit time using new techniques;
3. To determine the effect of bolus consistency, temperature, and head position on swallowing and kinematic pharyngeal transit times;
4. To develop and validate specific remedial rehabilitation techniques for individuals with neuromuscular disease. Data are still being selected and analyzed. Results are not yet available.

Nancy Seyden, from the above Rehabilitation and Neuromuscular Diseases Research and Training Center, reports that she received more than 500 requests to receive her Quality of Life Survey described in *Polio Network News* (Vol. 11, No. 2). Readers who volunteered to complete the survey will be receiving the comprehensive survey soon. Nancy was very pleased with the number of responses and encourages all who requested the survey to complete and return it. She is very interested in compiling the responses from the post-polio community.



In *POLIO NETWORK NEWS*, (Vol. 6, No. 4), in the article, "A Review of Swallowing Difficulties in Post-Polio Individuals," Roberta Simon, RN, offered these common-sense suggestions:

Chew slowly. Cook all foods until they are soft. Do not talk while eating. It can increase the risk of aspiration.

Avoid large bites and big gulps of liquid. Liquids are, at sometimes, managed better if the chin is tucked down to delay the swallow.

To control choking on saliva, avoid foods that thicken secretions, such as milk and milk products. Discuss calcium supplements with your physician if you do limit milk products. To control choking, eat in an upright position at all times.

Do not eat when fatigued. Consider eating several small meals each day. Combining different textured food makes eating and swallowing easier for some. Place a sauce or gravy on a dry, difficult-to-swallow food such as meat.

If liquids are a problem, thicken them with commercial starches or preparations to facilitate swallowing. Liquid soups are not recommended for individuals with tongue weakness. Cream soups are better tolerated as are juices with a thicker consistency such as nectars and tomato juice.

If taking medication is a problem, applesauce or jelly may help, and so may drinking water through a straw to get the medication to the back of the throat. It is a dangerous practice to elevate your chin to get the medication to the back of your throat. Raising your chin causes the vallecular space to disappear and swallowed material may drop directly into the airway. Avoid this practice.

Esophageal problems can be managed by eating in an upright position. Drinking a glass of water after eating helps in clearing the contents of the esophagus into the stomach. If a stricture is found during an esophageal evaluation, dilation may be needed.

If weakness is present on only one side of the throat, turning the head to the opposite side while swallowing is, at times, helpful.

Weight loss may be a problem and a high protein or high calorie liquid substitute is advised. Seek your physician's assistance so your nutritional intake may be monitored.

Surgical intervention is the extreme end of treatment for these difficulties. Care must be taken in any corrective surgical procedure because of the weak, underlying muscles.

Vocal cord weakness can be a problem for some and speech therapy is helpful in providing compensatory techniques. A small microphone to amplify the voice can be prescribed. Fatigue seems to play a role in vocal cord weakness.



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JUNE PRICE, editor of *LIVING SMART*, a newsletter for individuals living with spinal muscular atrophy, and Nicole Roberts, suggest the following from their personal experiences on ways individuals with swallowing problems can better cope with eating out.

Be honest with hosts ahead of time about your problem/needs. Tell people what you can and cannot eat. Sometimes it may be better to be up front and say no to their desire to feed you.

A solution at restaurants is simply to eat ahead of time, or after. Drink a protein shake before going to a friend's house and then nibble.

At restaurants, instead of a large meal, order an appetizer to be served with the dinner course. Salad bars are usually filled with soft peas, beans, cottage cheese, tomatoes, soups, sauces, puddings, as well as the hard-to-eat lettuce and crunchy, raw vegetables. Potato bars offer cream sauces and finely minced meat and vegetables.

Do not be afraid to ask for substitutions, or a reduced volume of food (so you do not have to stare at a huge plate of uneaten food). Make up your own meal. If all you want is a baked potato and applesauce, ask for it.

For more information about Living SMART or a complimentary issue, contact June Price, 3576 South 43rd Street, #32, Milwaukee, WI 53220-1550 (414/541-2848 voice and FAX; LivngSMART@aol.com).

SHARING EXPERIENCES

I am honored to tell my mother's story and have used her own words from letters and other documents as much as possible.

My mother, Bernice Alexander, New Jersey, had bulbar polio in 1948 at the age of 21. She was hospitalized for four months. Polio atrophied her vocal cords and her voice changed radically to a monotone. Atrophied neck muscles made swallowing and breathing difficult. At the most critical acute stage, due to the inability to swallow, she "drowned" from fluid in her lungs. She was brought back to life but had various problems with swallowing for the next 45 years. Reeducation was directed at swallowing, speech, and trying to turn and hold her head up. Physiotherapy focused on use of all her muscles: arms, legs, posture, etc. She learned to "balance" her head with the use of substitute muscles, primarily her hands.

The left side of her throat was worse than the right. She would chew her food VERY thoroughly, in small

bites, before attempting to swallow on the right side of her throat. Choking was not uncommon. These bouts of choking took quite a long time to subside due to the breathing difficulties. She would often use small pieces of bread or warm water to help dislodge whatever was stuck.

There were various stages of swallowing problems experienced due to post-polio syndrome. She started to avoid foods including tomatoes and other fruits and vegetables with seeds as well as most red meat. She preferred to eat custard, yogurt, chicken, and bananas.

After double pneumonia in 1989, she never seemed to regain full strength. She would be short of breath when walking and did not sleep well. After a New Jersey post-polio conference in 1990, she consulted a specialist in polio breathing problems who prescribed breathing support by using a Bi-PAP® machine while she slept. She used this for over six months and experienced better sleep and heightened mental alertness. However, the daily shortness of breath remained.

During the week of October 15, 1991, she had a minor head cold. Her voice was getting weaker but she did not realize it. On October 18th, her throat started to get sore, and by the next day, it was very sore. This was not the sort of sore throat associated with a respiratory infection. It was becoming more difficult for her to speak as the day progressed, due to the tightness in her throat and chest.

She was rushed to the hospital that evening. Her larynx and vocal chords were paralyzed. There was a lot of swelling so very little air could move through her trachea. Mom also had a low platelet count. Hematology support was required to raise the platelet level before a tracheostomy could be performed to allow her to breathe. After the tracheostomy, mom used a nebulizer at night instead of the Bi-PAP® machine.

Mom was very focused on obtaining more information on post-polio problems and participated in a study in January 1993, at Yale University by Dr. Carol Gracco and Dr. Carl Coelho. Food types of varying consistency were used and tested for her swallowing. The diagnosis read "pharyngeal transit was mildly decreased with minor pooling in the pyriform sinuses noted after each swallow. Subsequent dry swallows only partially cleared this status." The recommendation was to alternate liquid and solid swallows.

In a letter she sent to me, she said "I now have a different life living with a trach. The ambiguity of the situation is that my breathing, especially while sleeping is very much improved. The other side of the coin is the time and care involved in maintaining the trach. My low platelet count leaves me open to bleeding problems, and I have not been to work, a mall, or a movie since October. I wish I had understood my problems more clearly. When my breathing insufficiency was

diagnosed, I did not understand that the root cause was not any new involvement with my lungs or diaphragm, rather they were being affected on a secondary basis by the gradual weakening of my vocal chords and their inability to permit air to travel through them normally.”

Mom passed away on July 23, 1993, of lung cancer. She was a courageous lady with a very full life — raised a family on her own, cared for a home, pursued a professional career, traveled, and was actively involved in her church.

If mom were alive today, she would recommend that whatever problems you may have with post-polio syndrome, be it swallowing, breathing, etc., do not get discouraged. Seek out additional physicians. Help them to find more answers and better equipment to solve, or at least ease, the problems. Reach out and help them to help you and others.

Kim Johnson, Arizona

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Thank you for thinking of me. I hope my experience and suggestions are helpful.

Let me encourage anyone with swallowing and aspiration problems, and fatigue to the point where it is impossible to meet nutritional needs through using the canned formulas, (including adequate water intake, medications, etc.), to get a gastrostomy tube, also called a “stomach peg.” That is the route I chose in the summer of 1993, and I have never regretted it. The most important advantage is that I can control the fatigue of the swallowing muscles. Before the tube, the fatigue kept getting worse, and I was aspirating to the point of chronic bronchitis.

Another important advantage of my tube is that it solved my terrible anxiety about how I was going to eat and drink. My family, doctors, and even the nurses were amazed at all my anxiety. I was climbing the walls! It is amazing what you can get used to and even learn to love.

I can now take in some liquids and purees by mouth, but all my main nutrition goes in the tube. I eat no solid foods. Cool or cold water is difficult to control because it feels “slippery” in the mouth, so I take small sips of warm or hot water instead.

When my throat and mouth muscles are tired, all my liquids and formula go in the tube. I am not losing weight, am healthy, and lead a fairly normal life. Few people, except those I choose to tell, know. When I go to a restaurant, I order ice cream, which is easy for me to eat. I go to the pool for water exercising with no problem. My “balloon-type” tube needs to be replaced about every six months, which is an easy, pain-free procedure done in the physician’s office.

Another issue that is very important to me is speech. My throat and mouth muscles become easily fatigued by too much speaking. I take a pad and pencil with me wherever I go and use it to help control the fatigue. This takes a lot of self-discipline ... I would rather talk!

I also recommend someone with speech problems to see a speech therapist affiliated with a hospital to learn new speech habits. A therapist has worked with me to change my voice pitch and breathing patterns while speaking. I am now learning sign language, which is a big undertaking, but lots of fun and very interesting. I know that using a small microphone can help but, I have not tried that ... yet.

Talking on the telephone seems to be the most fatiguing of all, so I have a TDD and use it when I am really fatigued. Other than that, I try to space my calls and keep them short.

Patricia Novak, Ohio



Approaching Disability as a Life Course: The Theory

Jessica Scheer, PhD, National Rehabilitation Hospital Research Center, Washington, DC

I want to tell you today about a framework I have developed in collaboration with Mark Liborsky, a fellow anthropologist at the Philadelphia Geriatric Center, that may enable you to place your own experience with polio into a cultural context. We developed the framework through several years of in-depth, multiple-interview case studies of polio survivors.

Specifically, we looked at the significance of life-course stages and development tasks within an historical and medical context. We found that decisions about current disability-related issues are infused with broader concerns about personal identity and the fulfillment of personal and cultural expectations; and that early life experiences with disability continue to be important in later life.

Figures I and II illustrate a framework for examining personal experiences and concerns of polio survivors. The bottom line in Figure I, indicates the stages of the polio trajectory: Most of you can easily recount the type of rehabilitation you first received, the period of recovery and functional stability, and then, in many cases, the onset of new disabilities. Some of you experienced the new disabilities as second disabilities; others felt disabled for the very first time.

The axis of Figure I conveys the historic era during which you contracted polio. It serves as a general predictor of the type of rehabilitation you received and the societal attitudes towards polio and disabilities you encountered.

Within this medically oriented historical backdrop and at the intersection of the polio trajectory, some traditions developed among people who had polio about how to behave and how to perceive the world (see Figure I). Also during this time, when disabilities were viewed largely as a medical problem of the individual,

traditions developed in rehabilitation centers that were later reinforced in the family and other societal institutions. In those days, people were expected to be good patients — to comply with treatment recommendations and to fit into the mainstream of American life. Hearing “use it or lose it” over and over, those who had polio learned to fight for physical recovery, to exercise in spite of pain, and to generally push themselves to the limit and then push some more.

This effort led polio survivors to a heightened investment in the American work ethic as a way to moderate the social devaluation of people with disabilities. As they achieved self-sufficiency and productivity, they minimized and overcame their disabilities and passed into the mainstream.

Another early polio tradition that affected survivors was the message that they heard from rehabilitation

practitioners and society at large to forget their bout with polio: to put the past behind and to move on with their lives. Like the work ethic, putting the past behind was a broadly shared cultural expectation in the 1930s, '40s and '50s. Returning World War II veterans were told to do it, as were the people who did had devastating experiences during the Great Depression.

Perhaps the psychological process of initially minimizing losses has

survival benefits, as it certainly did during the first years of living with polio related disabilities. However, the tradition of putting the painful past behind is not one that lasts a lifetime. In fact, we are now observing the emergence of late-polio traditions: rehabilitation treatment that now requires people to conserve it or lose it; to slow down a bit; to make new priorities; and to stop trying to do everything. Devastating to a use-it-or-lose-it crowd, these new directives sound like orders to stop living.

Given this new, shared experience in adversity, many polio survivors are experiencing a new pride in their

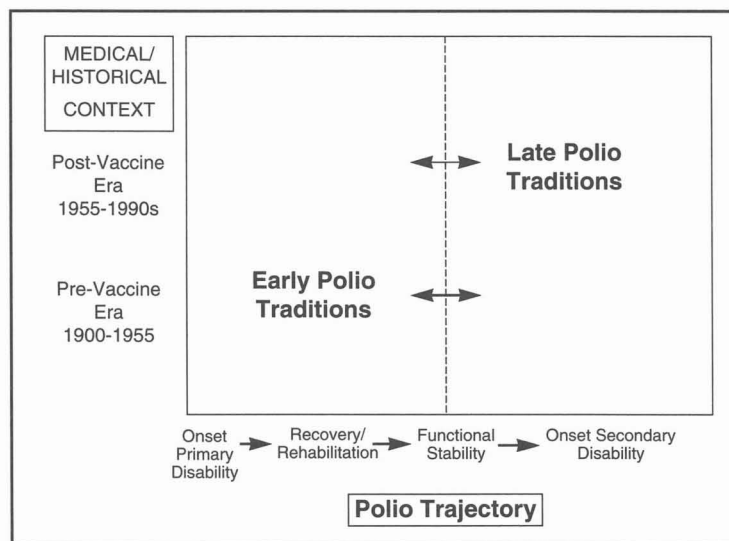


Figure I: Changing cultural contexts

polio, past and present. Some have found this pride in a support-group context, developing new respect for themselves and their life experiences as they meet others who have moved along a similar path, a pattern that I see happening here at these G.I.N.I. meetings.

In Figure II, we find the people who had polio. Their life stories, "polio biographie," are situated within life-course stages — childhood to old age — and developmental tasks — learning how to become a mature adult over a life span.

As an example of our framework in action, let's consider the biography of Gina Stafford, who had never used mobility devices but who has weakened muscles in her stomach and back and has walked with a limp since her childhood polio. Two years before coming to the post-polio clinic, she started to experience difficulty in rising from chairs and using stairs, and she grew fatigued when she walked more than a few blocks. Her family's hiking trips stopped,

a loss they all felt. After learning about how the late effects of polio were affecting her body, she changed some of her daily activities. She napped each afternoon before she got completely pooped out. She swam twice each week and got a handicapped-parking license tag.

Then she realized that her previously talkative 13-year-old daughter was increasingly silent around her. And one day her daughter exploded with a confession that she was embarrassed to be seen by her friends in a car with those license plates. "Why can't you be like other moms? Why are you so different?" she asked.

Although Mrs. Stafford was aware that her daughter's need for her to be like other moms was a normal part of adolescence, the child's reaction increased her own anxiety. How would her children perceive her if one day she needed a wheelchair, and, perhaps more significantly, how would she perceive herself?

Mrs. Stafford's life course was being disrupted dramatically. The way that she had expected herself to parent her children had been altered by the onset of post-polio weakness and fatigue. She was having to learn to accept new limitations — a new step in maturity — while having to teach her children to live with a mother who had limitations — a new step in being a parent. She spends a lot of time worrying about the future and her children.

Another woman, Kate McCall, was a 79-year-old retired social worker who had walked with a limp since she had polio as a child. She came to the clinic to learn how to manage new leg pain, weakness, and more frequent falls. The rehabilitation team advised her to use braces and crutches and to swim as often as she could. She went to the neighborhood heated pool several mornings each week and began to meet other older women who had arthritis and were also swim-

ming to help manage their pain. She glowed with pleasure as she spoke about the camaraderie she found among her fellow swimmers, who looked to her for guidance based on her lifetime experience with disability. "I didn't realize I knew anything being disabled until they asked me," she said. "I'm an expert, and I didn't even know it."

Finding other women her age who were also limited in what they could do helped Mrs. McCall face her own

daily struggles with better humor and spirit. She found new energy for starting the family quilt she had promised to make her children from their baby clothes. Her husband and children were thrilled to watch her develop a new interest that fit her current lifestyle. Indeed, Mrs. McCall learned to transcend her limitations by becoming engaged with the challenges of her retirement years.

One of the values of our framework is to alert rehabilitation professionals to the dynamics of living with lifetime disabilities. For polio survivors, the early polio traditions can function as both a source of distress when facing new functional losses or as a valuable resource when trying to adapt to them. For example, consider the polio tradition of working hard to meet goals and to overcome adversity: Mrs. Stafford had to work to discipline herself to cut back on her activities; a new skill she could well share with her children.

Given your new insight into these early and late-polio traditions, perhaps you can now use the life-course perspective to gain insight into the shaping of your own life and to help you to answer the question "And now what?" that faces you each morning. □

The next issue of *Polio Network News* (Vol. 12, No. 2) will continue the presentations from the session *Living with Disability: Perspectives*.

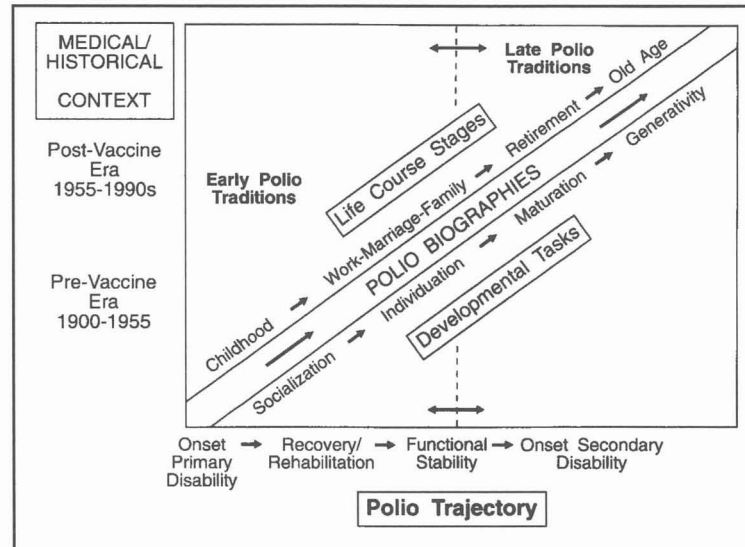
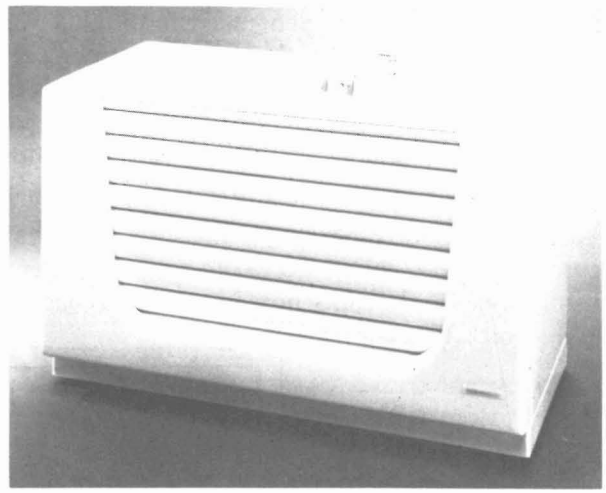


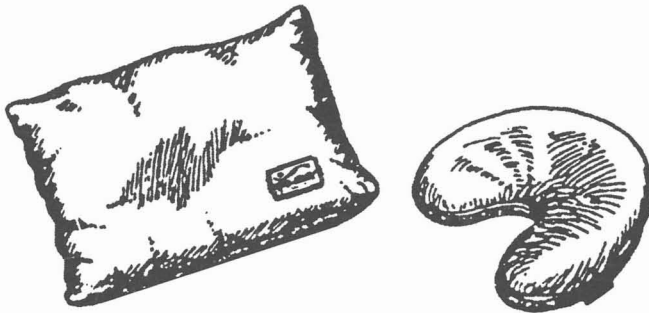
Figure II: Cultural contexts of polio biographies



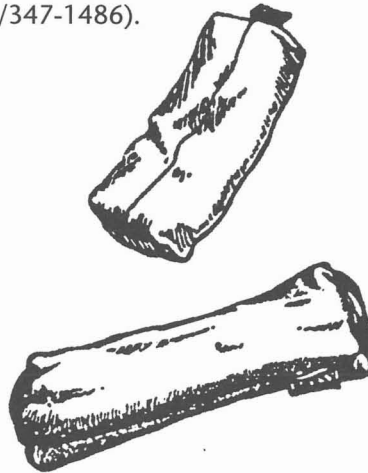
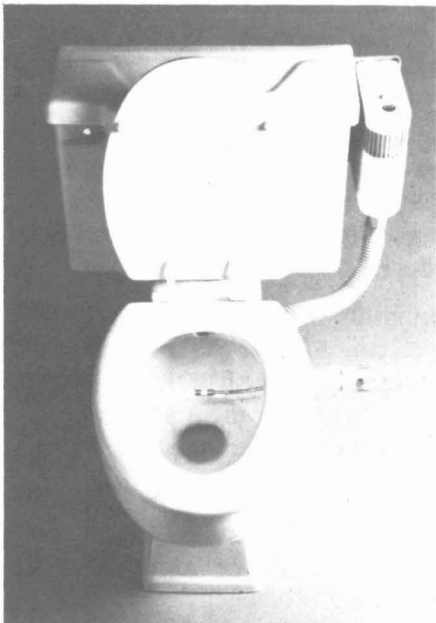
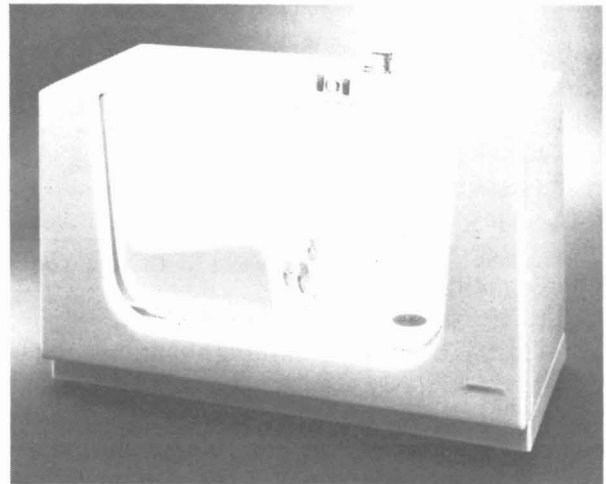
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THE RAMP PROJECT

The Ramp Project, a collaborative effort of the Metropolitan Center for Independent Living and the Minnesota Department of Economic Security, Division of Rehabilitation Services, was a finalist in the 1995 Ford Foundation "Innovations in American Government" award program. The Ramp Project provides information and assistance to individuals and families to resolve home access problems. A modular, reusable wheelchair ramp design, developed in 1992, reduces costs, is faster and easier to construct and is easily moved and reused at other locations. An alternative method of improving access for those with some walking ability has also been created. Long-tread, low-riser steps (also modular and reusable) are easier than ramps for many people to walk on.

The Ramp Project has distributed a construction manual, *How to Build Ramps for Home Accessibility* (available from DRAGnet on-line as a download file under the name RAMPMAN1.ZIP; for assistance call 612/338-2535), and an accompanying video, "Home Access Solutions: Ramps and Stairs," to the Centers for Independent Living (CIL) nationwide. Contact the closest CIL to view the video.

A one-hour television program, The Ramp Project Teleconference, will be broadcast by satellite on March 25th, 1996. Contact Bob Zimmermann at 612/628-6916 for time and technical details for the teleconference. To help make this video available in your area, call your Local Cable Access channel (not your local cable company) and request that they tape the broadcast and show it locally. □

CALENDAR

... 1996 ...

Post-Polio Options, MARCH 16, Bethesda Marriott Hotel, Bethesda, MD. Contact: Polio Society, 4200 Wisconsin Avenue, NW, Suite 106273, Washington, DC 20016 (301/897-8180).

The Late Effects of Polio/What Do I Do Now?, MARCH 23, Charleston Marriott Hotel, Charleston, SC. Contact: Jane Condon, P.O. Box 335, Folly Beach, SC 29439 (803/588-6438).

Everything Old Is New Again, American Occupational Therapy Association's 76th Annual Meeting, APRIL 20-24, Chicago, IL. Polio survivors Roberta E. Simon, RN, Nancy L. Caverly, OTR/C, and Joan L. Headley will present a workshop entitled Post-Polio Syndrome: An Old Adversary Revisited, 9-11 A.M., Tuesday, April 23rd. Contact: AOTA, 4720 Montgomery Lane, P.O. Box 31220, Bethesda, MD 20824-1220 (301/652-2682).

Third Luncheon Forum, May 4, Lehigh Valley Holiday Inn, Bethlehem, PA. Contact: Joanne Ross Gray, Easter Seal Society, 2200 Industrial Dr., Bethlehem, PA 18017 (610/866-8092).

Post-Polio — A Complete Overview, June 21-23, Daytona Beach, FL. Contact: Barbara Goldstein, Florida East Coast Post-Polio Support Group, 12 Eclipse Trail, Ormond Beach, FL 32174 (904/676-2435).

... 1997 ...

G.I.N.I.'s Seventh International Post-Polio and Independent Living Conference, May 28-31, 1997, St. Louis Marriott Pavilion Downtown. □

AN EXERCISE SUITABLE FOR ALL POLIO SURVIVORS

Exercise your right to vote. *Statistics on the disability vote indicate that 49 million Americans, or 19.4% of the population, or almost one out of every five people has a disability. Twenty-five million Americans with disabilities are registered voters. In 1992, 10% of all voters had disabilities. Of all registered voters with disabilities: 54% are registered as Democrats, 24% are registered as Republicans.*

Are you registered to vote? "The National Voter Registration Act" (NVRA or P.L. 103-31) signed into law in May of 1993 accomplished the goal of furthering full voting registration by requiring states to offer voter registration services.

In most states, voter registration application can be found at motor vehicle offices, social service agencies such as SSA, the Welfare Office, and private social agencies, or at public forums when candidates speak, or in candidate's campaign offices. The Secretary of State in each state capitol can also provide you information on how you can vote and to tell you of the deadline for registration in your state. (Lawsuits have occurred in 11 states where governors or legislatures refused to comply with the mandate of the NVRA. Five court decisions in three states have all been decided in favor of the NVRA.)

Getting out to vote. The Voting Accessibility for the Elderly and Handicapped Act of 1984 (P.L. 98-435) states

that "any handicapped or elderly voter assigned to an inaccessible polling place, upon advance request of such voter (pursuant to procedures established by the chief election officer of the state) will be assigned to an accessible polling place or will be provided with an alternative means for casting a ballot on the day of election." [Sec. 3(a)(1)(B)]. This act also states in Federal elections that "no notarization or medical certification shall be required of a handicapped voter with respect to an absentee ballot or an application for such ballot, except that medical certification may be required when the certification establishes eligibility, under state law ..." [Sec. 5(b)]. In other words, medical certification or notification cannot be required in order to vote in Federal elections. However, the procedures may be different for local elections. Check with your local election board.

Whom to call in your state. The January 1996, *Word From Washington* published by the United Cerebral Palsy Associations, featured "A Nonpartisan Guide to Voting." They encourage that the information be broadly disseminated. For a list of chief election officers by state; list of deadlines for registering to vote by state; one-page sheet with Techniques to Access the Disability Vote for Candidates Running for Office & Disability Litmus Test: How to Access the Candidates, contact International Polio Network.



LOOKING FOR ...

... **Rev. Orren Yuel Evans**, 2405 Pistachio Dr., Irving, Texas 75063 is trying to locate John M. Denman, a college buddy who began aeronautical engineering at the University of Cincinnati in 1944.

... **Kay (Pruitt Beauchamp) Gilley**, 2210 Oakridge Ln., Malabar, Florida 32950, and her sister, Irene, would like to hear from Dottie Pruitt.

... **Gilles and France Groleau**, 164 Mack St., Kingston, Ontario K7L 1P4 Canada are searching for Suzanne Levine, originally from Wisconsin who moved to the Daytona Beach area in the '70s.

... **Nancy Schuessler (McClay)**, 6130 Camino Real, Space 295, Riverside, California 92509, is looking for Ruthie Dunkirken, her roommate at Riverside Hospital in 1949-1950.

... **Peg Kehret**, 2244 Southeast Fourth, Redmond, Washington 98053 is searching for Dr. William Bevis, who was at the University of Minnesota Hospital, Minneapolis, Minnesota and Althea Ballard, who was at Sheltering Arms in Minneapolis in 1948-49.

"I am selling my Florida home which has many accessibility features." For more information, contact: **Michael L. Avery**, 41 Da Rosa Ave., DeBary, Florida 32713.

"I am 58 years old and had polio at age eight. I am now having some weird symptoms — slurred speech, swallowing problems, pain, numbness, and severe tremors. I have had all the tests, and there is no diagnosis as yet. I have been a golf course superintendent, or groundskeeper, for years. I am interested in speaking with anyone who had polio who has worked extensively with chemicals such as would be used on a golf course." Write **James E. O'Kelley**, 108 7th St., Columbus, Georgia 31901.

"My one leg is two inches shorter than the other, and I have been doing gentle aquatic exercises which are helpful, except I can not wear my leather shoes and lift in the water, so my back hurts. Does anyone have a suggestion as to what I can wear in the pool?" **Beulah Barnes**, Rte. 7, Box 158, Corinth, Mississippi 38854.

"For the last two years, I have experienced severe eye pain upon awakening each morning. The pain, that feels as though someone is sticking needles in my eyes, has become unbearable, breaking through my pain medication and waking me several times throughout the night. There are no abrasions showing on my corneas, and it has finally been determined that my eyelids no longer close completely, because the nerves that control the opening and closing of my eyes are

deteriorating. As I sleep, my corneas dry out and that is responsible for the severe pain. I am now applying a salve to my eyes before I sleep and artificial tears several times throughout the night when I awaken. Recently, my pain management physician suggested that I tape my eyelids shut with surgical tape for more comfort and demonstrated the procedure that is used with individuals experiencing the same problem due to stroke, head injury, and other neuromuscular diseases. If anyone has found other methods that offer more comfort, I would appreciate hearing from you."

Caroleanne Green, 741 Gullwing Lane, North Las Vegas, Nevada 89031.

"What I would like to suggest is a *Battle with Bracing, Part III* in which we get down to the business of the braces themselves. I have seen articles extolling developments in prosthetics. Has there been any real transference of this technology to orthotics? I would like to see orthotics get the same kind of attention and funding as prosthetics." **Richard B. Rice**, McArthur, California.

Polio Network News has solicited and received information for a third article on bracing to be published in a future issue. If you have leads or suggestions, please contact International Polio Network. □

POST-POLIO BIBLIOGRAPHY

Post-Polio Syndrome: Pathophysiology and Clinical Management by Anne Carrington Gawne, MD, and Lauro S. Halstead, MD, *Critical Reviews in Physical and Rehabilitation Medicine*, Vol. 7, Issue 2, 1995, pp: 147-188.

An Open Trial of Pyridostigmine in Post-Poliomyelitis Syndrome by Daria A. Trojan, MD, and Neil R. Cashman, MD, *The Canadian Journal of Neurological Sciences*, Vol. 22, No. 3, August 1995, pp: 223-227.

"In patients with PPS, conditions causing fatigue such as other neurological disorders, depression, and a variety of medical diseases must be considered and treated before attributing patient fatigue to PPS. If fatigue is believed to be due to PPS, then conservative measures such as weight loss, energy conservation techniques, better organization of daily activities, and planned short rest periods or naps during the day may be beneficial. If these measures are ineffective or insufficient, treatment with pyridostigmine may be warranted in some cases." The article contains several contraindications to pyridostigmine.

The authors called for a therapeutic trial of pyridostigmine which will start soon. Six North American medical centers will test the hypothesis that oral pyridostigmine, by improving function and integrity of distal motor units, will result in an improvement in fatigue, weakness, endurance, and general health status in individuals with post-polio syndrome. □

INFORMATION AVAILABLE FROM INTERNATIONAL POLIO NETWORK

Post-Polio Directory — 1996 contains four sections. The International section lists contacts in countries throughout the world interested in post-polio and disability issues. The entries for the U.S. are divided into three categories. Physicians and facilities providing specialized and comprehensive treatment for polio survivors are listed under Clinics. Many individual health professionals have expertise in treating polio survivors and are listed along with their areas of medical specialties under Health Professionals. The Support Group section lists support groups, along with a contact person. Some names listed are resource only and are designated as such.

Post-Polio Directory — 1996 is for information purposes only. A listing does not imply endorsement by the International Polio Network.

The cost of the Directory is \$4 USA; \$5 Canada, Mexico, and overseas surface; \$6 overseas air (US funds only).

Back issues of **Polio Network News** from 1990 (Vol. 6) — 1995 (Vol. 11) are available for \$3 each issue (not each article). Below is a list of featured topics and the volume and number of *Polio Network News* in which they appear. A yearly subscription to *Polio Network News* is \$16 USA; \$21 Canada, Mexico, and overseas surface; \$25 overseas air (US funds only).

- Let's Talk About Oxygen and Polio (Vol. 6, No. 3)
- The Diagnosis of Underventilation Following Polio, and Treatment of Underventilation by Day and by Night (Vol. 6, No. 3)
- Post-Polio Breathing and Sleep Problems (Vol. 11, No. 4)
- New Breathing Problems in Aging Polio Survivors (Vol. 11, No. 4)
- Vignettes ... of Polio Survivors Using Ventilation Assistance (Vol. 11, No. 4)
- Thoughts on Self-Help (Vol. 7, No. 1)
- People Keep Coming: The Brief Story of a Support Group (Vol. 7, No. 4)
- A Post-Polio "Normal's" Reconciliation with the Ghost of Polio Past, Part II (Vol. 6, No. 1)
- A Fresh Look at the Type A Personality? (Vol. 10, No. 1)
- We Call Ourselves Survivors (Vol. 10, No. 1)
- Polio Survivors Remember (Vol. 11, No. 1)
- Hydrotherapy Program for Patients with the Post-Polio Syndrome (Vol. 6, No. 1)
- A Case for Re-evaluating Physical Therapy as a Viable Extended Treatment of Polio Individuals in the 1990s, Part I (Vol. 7, No. 3), Part II (Vol. 7, No. 4)
- Becoming an Intelligent Consumer of Physical Therapy Services, Part I (Vol. 9, No. 1) Part II (Vol. 9, No. 2)
- Tips on Shopping for a Scooter (Vol. 10, No. 2)
- Coordinating Post-Polio Treatment: You, Your Primary Physician, and Your Expectations (Vol. 11, No. 2)

- US Post-Polio Clinic Survey Results (Vol. 8, No. 3)
- Post-Polio Syndrome 101: Acute Polio and Post-Polio Theories (Vol. 10, No. 4)
- Defining Post-Polio Problems (Vol. 11, No. 1)
- Incidence and Prevalence of Post-Polio Problems (Vol. 11, No. 1)
- Prescription for Fatigue (Vol. 6, No. 2)
- Prescription for Weakness (Vol. 6, No. 3, Vol. 7, No. 1)
- Prescription for Pain (Vol. 6, No. 4)
- A Review of Swallowing Difficulties in Post-Polio Individuals (Vol. 6, No. 4)
- A Look at Carpal Tunnel Syndrome (Vol. 7, No. 2)
- A Ten Year Experience (Vol. 7, No. 2)
- The Latest from the Later Life Effects (LLE) Study (Vol. 11, No. 1)
- Suggestions for Exercise (Vol. 7, No. 3)
- Scoliosis (Vol. 8, No. 2, Vol. 8, No. 4)
- Braces do not Mean Ugly Shoes (Vol. 8, No. 1)
- The Battle with Bracing, Part I: Scoliosis (Vol. 11, No. 2)
- The Battle with Bracing, Part II: Choosing an Orthotist (Vol. 11, No. 3)
- Exploring Your Options (re: surgery) (Vol. 8, No. 2)
- Post-Polio Corrective Surgery: Then and Now (Vol. 11, No. 3)
- Post-Polio Corrective Spinal Surgery (Vol. 11, No. 3)
- Facing Surgery when Breathing is a Problem (Vol. 11, No. 4)
- What's Happening with Research Medications (Vol. 8, No. 4)
- Osteoporosis (Vol. 9, No. 3)
- Nutrition Odds and Ends (Vol. 9, No. 4)
- The Global Eradication of Polio — A Progress Report (Vol. 10, No. 2)
- Status of Polio in the World Today (Vol. 10, No. 3)
- Disability, Polio, and the Late Effects in China (Vol. 11, No. 2)
- U.S. Polio Vaccine Policy Under Review (Vol. 11, No. 3)

The Late Effects of Polio — An Overview, has been updated. Five copies of the pamphlet are available free of charge. Other quantities are available as follows: 6-25 copies \$4; 26-50 copies \$8; 51-75 copies \$12; 75-100 copies \$16.

I.V.U.N. News is a biannual newsletter edited by Judith Raymond Fischer providing information and networking for ventilator users, their families, and health professionals committed to home mechanical ventilation. A yearly subscription to *I.V.U.N. News* is \$12 USA; \$15 Canada, Mexico, and overseas surface; \$17 overseas air (US funds).

To order, send request and check payable to G.I.N.I., 4207 Lindell Blvd., #110, St. Louis, MO 63108-2915.

**NOTE:
New Address!!**

WHO Reiterates Support of Oral Polio Vaccine

"The eradication from the world can only be achieved using oral polio vaccine," said Dr. Jong-Wook Lee, Director of the Global Program for Vaccines, commenting on a decision by the Centers for Disease Control and Prevention (CDC) in the United States of America to recommend adding two doses of injectable polio vaccine (IPV) to the national immunization schedule.

"The core group working towards global polio eradication, the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), CDC and Rotary International, emphasize that oral polio vaccine (OPV) is recommended because it can provide both individual protection to each child, as well as prevent the spread of the poliovirus to other children," points out Dr. Lee. At US\$ 0.08 per dose, the cost of a single dose of OPV procured by UNICEF is less than one tenth the cost of a dose of IPV.

The Advisory Committee on Immunization Practices (ACIP) statement applies only to the United States where the last case of naturally occurring polio was registered more than 15 years ago. WHO reaffirms its position that OPV alone is the basis for the global eradication of polio, and that the addition of IPV is neither necessary nor recommended for this purpose.

The ACIP meeting at the Centers for Disease Control voted on Wednesday (October 18), to change the immunization schedule in the United States to two doses of injectable polio vaccine and two doses of oral polio vaccine. In their recommendation, the ACIP affirmed its support for WHO's initiative to eradicate polio and noted that the eradication of polio was achieved in the United States through the exclusive use of the oral polio vaccine.

"The change in ACIP's position seems to be based on fears of polio caused by the vaccine," says Dr. Lee. "Vaccine associated polio occurs at a rate of about one case per three million doses administered." The new

ACIP strategy will prevent only about half of the five to ten cases of vaccine associated polio in the United States each year at a cost of approximately US\$ 20 million.

WHO estimates that as many as 100,000 cases of polio occurred worldwide in 1994. The initiative to eradicate polio seeks to destroy totally the wild (naturally occurring) polio virus from the entire world by the year 2000. When the disease is eradicated, immunization against polio will no longer be necessary. The United States will save at least US\$230 million each year after polio is eradicated and immunization is stopped. The global savings from polio eradication are expected to total at least US\$ 1.5 billion per year. □

Source: *EPI Newsletter* (Expanded Program on Immunization)
Pan American Health Organization, Washington, DC 20037 USA

Proposed Flat Tax on Vaccines

U.S. Congress is now considering a flat tax on vaccines. The tax is levied by Congress to fund awards made under the Vaccine Injury Compensation Act of 1988 following adjudication of claims for injuries as a result of public health immunization programs.

The proposed flat tax is 51 cents per antigen/disease. Under the proposal, the current tax on diphtheria and tetanus toxoids and pertussis (DTP) vaccine of \$4.56 per dose would drop to \$1.53 per dose — 51 cents for each antigen. Both oral and inactivated poliomyelitis vaccines, which currently are taxed 29 cents per dose each, would have their tax increased to 51 cents.

Excerpted from *JAMA*, November 15, 1995 —
Vol. 274, No. 19.